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ABSTRACT

This paper examines the legal mandates as well as the definitions and indicators for a family-centered early childhood system of care for children with special needs. Legislation discussed includes the Individuals with Disabilities Education Act and the Maternal and Child Health Block Grant (Title V of the Social Security Act). Various definitions of family-centered early intervention systems are presented. The sets of standards and indicators of quality care developed by the Association for the Care of Children's Health, New England Serve, the Family Resource Coalition, and the Consortium of Family Organizations are described, and examples of indicators are listed in the areas of individualized services, health care professional and team characteristics, health care agency or facility responsibilities, state health department responsibilities, and guidelines for community and societal supports. The paper concludes with five recommendations for assuring a family-centered early intervention system. (Contains 27 references.) (JDD)

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# BUILDING A FAMILY-CENTERED EARLY INTERVENTION SYSTEM

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## Importance of a Family-Centered Early Intervention System

The status and value of the family are among the most fundamentally acclaimed virtues in American society. Although their stated importance in political and religious circles is not always implemented in social policies, the goal of having family-centered policies, programs, services and systems of care is a logical outgrowth of the American philosophy and democratic values.

The implementation of family-centered programs and policies is a goal in education. Because parents are theoretically involved in their children's education through public school processes, the potential for family involvement and family direction is great. Educational research has documented the value of parent involvement and parent control in education (Pizzo, 1983). In addition, the state and federal special education reforms in the 1970s specifically gave parents of children with special needs access and due process rights to the educational assessments and plans for their children (Butler & Singer, 1987).

Other precursors to the notion of family-centered care can be found in the parent and consumer movements in the 1960s and early 1970s. The so-called "War on Poverty" programs such as Head Start empowered parents and families to shape services for themselves and their children (Zigler & Valentine, 1979). Many of the early childhood and educational programs included strong parent involvement initiatives (Hauser-Cram, Pierson, Walker & Tivnan, 1991; Hechinger, 1986). In many cases, parent involvement and control through boards of community-based organizations are responsible for the continuation and direction of early childhood programs such as Head Start as well as health care provided through migrant and community health centers.

The tradition of self-help groups in the health and human service fields is also a precursor to the notion of family-centered care. Examples of a strong involvement by consumers or parents are: the work of the women's health network, which began with the first publication of *Our Bodies, Ourselves* by the Boston Women's Health Book Collective; Mothers Against Drunk Driving (MADD); the families affected by an infant death to Sudden Infant Death Syndrome (SIDS); and parents involved in the de-institutionalization movement for individuals with mental retardation and mental illness. Many social movements have, in fact, been shaped by the involvement of parents and consumers (Pizzo, 1983).

The notion of family-centered care in the health field is a more recent phenomenon, which gained prominence in the 1980s. It is no surprise to find that family-centered care is not a mainstream notion in medical and health settings; the health system–unlike education–is not universally or publicly provided in our society. Because health care is not an entitlement or a right for children and youth, there is no universal system or one place to go if there is a problem with health care. There is no equivalent of the local school board for accountability. Unlike education in America, most of health care is financed through private sector dollars rather than public dollars (Schlesinger & Eisenberg, 1990). Additionally, active family or parent involvement is a relatively new concept in medical and health settings, which traditionally follow

a hierarchical medical model based on the physician's having the knowledge and being the manager of the patient's health care.

During the past decade there has been an increased recognition that health care–especially that of children with special needs and their families–must be family-centered (Shelton, Jeppson & Johnson, 1987). As Schorr stated (1980), "Not only is the family the primary unit for the delivery of health services to infants and children, but the family environment is probably the greatest influence on the child's health; the family is not only the principal influence upon a child's development, it is also the intermediary between the child and the outside world, including the health care system." Hence, it is logical that there needs to be a family-centered system of health care and related services.

The World Health Organization defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity" (1978). If our definition of "health" is as expansive as that, then all early intervention services and programs can be argued to be a part of the health system. An early intervention system of services operates in a context of a larger public health, education and social service system. Depending on the state and locality, different terms will be used for the parts of the system. Because the health care system is the only one with which all parents will likely have interaction from the birth of their child through their third birthday, it conceptually makes sense to design an early intervention system that is integrated and embedded in the primary health care system in a community. Regardless of the terms used, it is reasonable to desire that the early intervention system be "family-centered." If the system is family-centered, it implies that the early intervention services and programs are, as well. The reverse is not necessarily true, however; family-centered programs and service components are certainly necessary, but these components alone are not sufficient to ensure that the entire system is "family- centered."

This paper will examine the legal mandates as well as definitions and indicators for a family-centered early childhood system of care. After a brief summary of how well family-centered systems are being implemented today, recommendations for how to build and institutionalize them in the future will be presented.

**Legislative Mandates**

There are only two pieces of federal legislation which mandate the development of a population-based system of care for children with special needs: the Individuals with Disabilities Education Act (IDEA) and the Maternal and Child Health Block Grant (Title V of the Social Security Act). Both specify the development of systems of care that involve and are sensitive to the needs of families; both share the vision of a family-centered system of services for young children and their families.

Although other pieces of federal legislation (e.g., Developmental Disabilities Act, Title XIX/Medicaid, Child Care Block Grant, Family Support Act) authorize family support, choice, and involvement, none is as comprehensive, nor mandates a "systems" rather than a "program component" perspective, as

do Title V and IDEA. There is a clear push for family-centered care by researchers and policymakers who advocate for welfare reform (Allen, 1991) and the establishment of family resource and other preventive programs at the community level (Ooms, 1991; Weiss & Halpern, 1990).

Subchapter VII–Infants and Toddlers with Disabilities–of IDEA (formerly Part H, Public Law 99-457) mandates "the policy of the United States to provide financial assistance to States–to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency program of early intervention services for infants and toddlers with disabilities and their families." Clearly, the intent of Subchapter VII of IDEA is the development of an early intervention system using all programs, agencies, and funding streams within a state to meet the needs of eligible infants and toddlers, as defined in the state plan (Garwood & Sheehan, 1989). This reauthorization of Public Laws 94-142 and 99-457 into IDEA extends the original notions of parental consent and involvement in "family-implemented" interventions as outlined in individualized educational plans to those of family involvement in "family-based" interventions that include the entire family unit in Individualized Family Service Plans (Kaiser & Hemmeter, 1989).

Although the 14 minimum components mandate key pieces needed in an early intervention system of care, issues of how the early intervention system fits within an overall system of care for all children are not explicitly addressed (with perhaps the exception of the child find system and public awareness campaign) and only 1 of the 14 components refers to families explicitly (e.g., the development individualized family service plans for each infant and toddler served).

Even though only 1 of the 14 components explicitly refers to families (the requirement that every family have an Individualized Family Service Plan with major participation by the family), there is little doubt that the law is designed to empower parents. The requirement that three parents be named to the Interagency Coordinating Council and the desire to assess the strengths and needs of the family before plans are made are two other indicators, as is the preamble to the law itself:

> The Congress finds that there is an urgent and substantial need to enhance the capacity of families to meet the special needs of their infants and toddlers with handicaps (100 STAT.1145)

Because the statute and regulations governing the program are not specific in defining a system that is family-centered, it is not clear whether or not all policy-makers, providers, and parents view the development of a family-centered system in the same way. Much of the guidance and technical assistance at the federal level (National Center for Clinical Infant Programs, Carolina Policy Studies, National Early Childhood Technical Assistance Service, Georgetown University, etc.) highlighted the value and importance of parent participation and involvement as key elements of a family-centered set of services.

The other federal legislation that clearly mandates a family-centered system of care is Title V of the Social Security Act, as amended by the Omnibus Budget Reconciliation Act (OBRA) of 1989 (Public Law 100-239). OBRA'89 requires states "to provide and to promote family-centered, community-based, coordinated care (including care coordination services) for children with special health needs and to facilitate the development of community-based systems of services for such children and their families." The maternal and child health block grant application guidance requires states to explicate their plans for developing and implementing community-based systems of care within a statewide system of care. The law has focused on family-centered philosophy:

> For services for children with special health care needs, authorizes States to provide and promote family-centered, community-based, coordinated care (including care coordination services) for children with special health care needs and to facilitate the development of community-based systems of services.

The legislation gives public health agencies the clear leadership for the planning and implementation of a system of care for all children, including children with special needs. Title V also requires that 30% of state funds be spent on children with special health care needs; states may define the children and services included as they wish. In actuality, all of the services in the Title V block grant are important and are part of the system of care for children with special needs; the other portions of the legislation deal with prenatal care, as well as preventative and primary care.

Although the law does not clearly specify this in detail, the systems-building activities required by Title V are consistent with public health functions as recently outlined in the Institute of Medicine (1988) report on the state of public health in the nation. Public health agencies are responsible for needs assessment, planning, policy development, interagency collaboration, health promotion and prevention activities, education and technical assistance, surveillance, program monitoring and evaluation, provision of direct services where needed, and quality assurance. Although not acknowledged or understood widely, it is a fact that public health agencies provide the infrastructure for the organization and delivery of health care for child and adolescent populations, regardless of who pays for and provides the care. Therefore, to meet the OBRA'89 mandates, public health agencies must assume a leadership role for the development of health systems by using all the public leverages at their disposal (e.g., funding, staffing, regulation and licensing) to build systems of care. The explicit statement of the public health systems-building role with respect to children with special needs in the OBRA'89 legislation has been a real support for all states as they assume the new roles in addition to the provision of direct services to children and their families.

The development of these systems of care has been adopted by the federal Department of Health and Human Services as an objective for Healthy Children 2000: "Increase to 50 the number of states that have service systems for children with or at risk of chronic and disabling conditions, as required by

Public Law 101-239 (Objective 17.20)." Information and data from states' annual reports to the Maternal and Child Health Bureau will provide the main source of information for monitoring progress towards this objective.

**Definition and Indicators of a Family-Centered Early Intervention System**

Before a family-centered early intervention system can be designed and implemented, there needs to be a clear statement of what such a system is. More specifically, what are the characteristics of a family-centered system which could be assessed over time to assure that the system exists and is maintained. How can the values of family-centeredness be translated into definable and clearly measured outcome objectives? Without this specification, there is the tendency for the discussion to remain at an abstract and theoretical level without ever influencing policy and practice.

Although there is a lot of attention placed on the value of family-centered care and services (Brewer, McPherson, Magrab & Hutchins, 1989), there is very little to date that consistently defines the terms in very explicit ways. The two exceptions that stand out, however, are the work of the Association for the Care of Children's Health and New England SERVE. Both groups, funded by the Maternal and Child Health Bureau, have attempted to define the components of family-centered care.

Brewer et al. (1989) present the following definition of family-centered care as conceptualized by Shelton and her colleagues in the "red book" (Family-Centered Care for Children with Special Health Care Needs, 1987):

> Family-centered care is the focus of philosophy of care in which the pivotal role of the family is recognized and respected in the lives of children with special health needs. Within this philosophy is the idea that families should be supported in their natural care-giving and decision-making roles by building on their unique strengths as people and families. In this philosophy, patterns of living at home and in the community are promoted; parents and professionals are seen as equals in a partnership committed to the development of optimal quality in the delivery of all levels of health care. To achieve this, elements of family-centered care and community-based care must be carefully interwoven into a full and effective coordination of the care of all children with special health needs. (p. 1055)

This notion of family-centered care involves more than one component of care; hence, family involvement does not imply that a program component or system is family-centered. Shelton et al. (1987) describe the elements of this new family-centered philosophy of care as moving away from an institution/agency approach and a child-centered approach to a family-centered approach. In fact, a system of family-centered care with a family at the center of the service system world rather than the family as an appendage to the existing service system necessitates that a "Copernican Revolution" in the care of children with special needs is needed (Turnbull & Summers, 1985). The notion

that a parent or family should be an equal partner–and even sometimes the leader–in the care of the child is a radical idea in health care and social services.

Shelton, et al. (1987), using their definition and philosophy of care, have outlined the following elements of family-centered care:

1. Recognition that the family is the constant in the child's life while the service systems and personnel within those systems fluctuate

2. Facilitation of parent/professional collaboration at all levels of health care:
   - care of an individual child
   - program development, implementation, and evaluation
   - policy formation

3. Sharing of unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner

4. Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families

5. Recognition of family strengths and individuality and respect for different methods of coping

6. Understanding and incorporating the developmental needs of infants, children, and adolescents and their families into health care delivery systems

7. Encouragement and facilitation of parent-to-parent support

8. Assurance that the design of health care delivery systems is flexible, accessible, and responsive to family needs

These elements have been incorporated into checklists with indicators, so that program assessments and systems monitoring can be conducted to assure that the family-centered elements are present. Checklists have been developed for several domains and components of the service system. These are listed below with an example of an item from each area:

**Effective Parent/Professional Collaboration**

Are collaborative meetings composed of equal numbers of parents and professionals?

Are there mechanisms for including parents along with professionals in inservice programs to build skills necessary for this collaboration on an ongoing basis?

**States**

Do parents participate collaboratively with professionals at all levels of decision making and policy formation within the state?

Do parents have complete and ready access to their children's records?

**Communities**

Are there services available that support families as they care for their children with special health needs? (List includes parent education programs, respite care programs, financial planning assistance, etc.)

**Professional Training Programs**

Are there opportunities for professionals to learn directly from parents about their perspectives and support needs?

Do parents participate in the development of training programs for professionals?

**Hospitals**

Is there a Parent Advisory Committee which reports to the Board of Directors?

Are there mechanisms for informing parents about hospital policies and programs?

**Research Investigations**

Is there a mechanism to ensure that the results of the research are communicated to families who participate?

Does the research design and data analysis reflect a balanced approach, focusing on family's strengths as well as needs?

The other major step in defining family-centered systems of care has been taken by New England Serve, a regional network for promoting services for children with special health care needs. Beginning with a set of values as goals for a desired system of care, a multidisciplinary Regional Task Force on Quality Assurance, which included several parents, developed a set of standards and indicators of quality care for children with special health care needs.

The set of values articulated at the beginning of the process are very similar to those adopted by the Massachusetts Department of Public Health for all family and community health programs, including the early intervention system. These goals for a system of care guide all maternal and child health

planning, policy development, program development and implementation, and resource allocation with state and federal dollars. The goals for a system of care are as follows:

- Is community-based
- Is family-centered
- Is coordinated
- Is comprehensive
- Is prevention-oriented
- Encourages normal living patterns
- Is available early and continuously
- Engages parents/consumers as partners with professionals
- Is responsive to cultural, language, and socioeconomic differences
- Uses a non-categorical approach
- Integrates health, education, and social service systems
- Meets quality standards of care
- Is flexible and adaptable to change

Using a similar set of goals for care, New England Serve developed a set of indicators of care that were responsive to five levels of a system of care, extending from the individual child's and family's contacts with the system to the community's and state's response. The document, entitled *Enhancing Quality* (Epstein, Taylor, Halberg, Gardner, Walker & Crocker, 1989), attempts to outline concrete indicators that can be used to assess the degree to which a system or part of the system meets the goals articulated above. Examples of indicators within each of the five areas are listed below:

**Individualized Services**

1.0 The child has representation through family membership on the health care team.

1.1 Family members participate in team decision-making regarding health care services and the development of the health care plan.

1.2 Expectations and roles of all team members are defined.

1.3 The family provides information regarding the child's strengths, needs, and culture, and feed-back regarding the services received.

1.4 Interpreter services are available.

3.0 The child/family has access to the health care record.

3.1 Families receive written information regarding record keeping policies, procedures, and their rights to full access to the records.

3.2 Copies of information from the health care record and explanations regarding the content of the health care record are provided to the family upon their request.

3.3 Families have the opportunity to enter written comments from the health care record.

3.4 Family consent is obtained when written information from the health care record is shared.

3.5 Families are encouraged and assisted to establish a portable record-keeping system in order to maintain and use information from the health care record.

**Health Care Professional and Team Characteristics**

24.0 Health care professionals inform families of available resources.

24.1 Referrals are made to agencies such as education, recreation, vocational assistance, mental health, and creative arts.

24.2 Information is provided on parent-to-parent and support services, including diagnostic-specific groups.

24.3 Families are encouraged to identify informal networks, (e.g., grandparents, neighbors, friends) and utilize them for support.

**Health Care Agency or Facility Responsibilities**

28.0 Agency operations are responsive to the needs of children and families.

28.1 The agency has a mission statement that includes a commitment to family participation at all levels.

28.2 The agency ensures that all programs and services are available to children and their families without discrimination based on race or ethnic identity, primary language, religion, gender, sexual orientation, marital status, medical condition, or method of payment.

28.3 The agency has a policy for ensuring that children receive care regardless of the ability to pay.

28.4 The agency has a mechanism in place that includes parent representatives to review ethical issues.

28.5 The agency has a procedure for ensuring that families are well-informed prior to giving consent for any treatment or procedure.

28.6 The agency maintains confidentiality of records and has written procedures for sharing information with others.

28.7 The agency ensures that the child and/or family has access to the health care record.

28.8 The agency supports its staff fulfilling their responsibilities for identifying, assisting, and reporting children at risk or potentially at risk for child neglect or abuse.

**State Health Department Responsibilities**

39.0 The State health department collaborates with a broad range of families, health care professionals, and advocacy groups on behalf of children with special health care needs.

39.1 On-going departmental advisory groups include family representatives, health care professionals, and advocacy groups.

39.2 Consultation is sought in the planning and review of specific programs and policies.

39.3 Parent participation is supported and may include travel and child care reimbursement and training.

39.4 Parent representatives reflect diverse cultural, racial, and socio-economic groups.

45.0 The State health department periodically reviews current and proposed state mandates for health services to ensure that they address the special health care needs of children.

45.1 State regulations for hospitals, including discharge planning guidelines, support family-centered care.

45.2 State mandated screening and immunization programs are periodically reviewed to determine whether they address the unique needs of children with special health care needs.

**Guidelines for Community and Societal Supports**

58.0 Family support programs and parent networks are promoted and financed.

58.1 A full range of family support services are available in the community (e.g., babysitting/day care, adaptive equipment exchanges, transportation, and advocacy services).

58.2 Parent networks are encouraged and widely publicized.

58.3 Support programs for parents and for brothers and sisters receive public and private funding.

58.4 Families receive respite care services so that they may participate in community life.

59.0 Families have access in their community to updated information and referral services.

59.1 Information and referral services are widely publicized.

59.2 Information and referral services are accessible at no cost.

59.3 A comprehensive range of child health and family support services are included.

Two other leaders in family programming and policies in the United States have articulated principles that relate to family-centered care. Although they overlap in some ways with the work of ACCH and New England SERVE, they are listed in their entirety.

The Family Resource Coalition (1991) published the following set of guiding principles for family resource programs in their 10th anniversary newsletter . All of the principles are based on the assumption that confident and competent parents are more likely to have healthy children, and that the presence of family empowerment mechanisms differentiates a family resource program from other programs or services. These principles are built on partnerships with parents:

> The basic relationship between program and family is one of equality and respect; the program's first priority is to establish and maintain this relationship as the vehicle through which growth and change can occur.
>
> Participants are a vital resource; programs facilitate parents' ability to serve as resources to each other, to participate in program decisions and governance, and to advocate for themselves in the broader community.

Programs are community-based and culturally and socially relevant to the families they serve; programs are often a bridge between families and other services outside the scope of the program.

Parent education, information about human development, and skill building for parents are essential elements of every program.

Programs are voluntary, and seeking support and information is viewed as a sign of family strength, not indicative of deficits and problems.

The Consortium of Family Organizations, in their Family Policy Report (1990)–which is issued "to assist policymakers in evaluating legislation and social programs from a family perspective"–outlined six guiding principles:

1. Family Support and Responsibilities: Policies and programs should aim to support and supplement family functioning and provide substitute services only as a last resort.

2. Family Membership and Stability: Whenever possible, policies and programs should encourage and reinforce family, parental, and marital commitment and stability, especially when children are involved.

3. Family Involvement and Interdependence: Policies and programs must recognize the strength and persistence of family ties, even when they are problematic.

4. Family Partnership and Empowerment: Policies and programs must consider families as partners when providing services to individuals.

5. Family Diversity: Families come in many forms and configurations, and policies and programs must take into account their different effects on different types of families. Policies and programs must recognize the diversity of family life, neither discriminating against nor penalizing families solely for reasons of structure, roles, cultural values, or life stage.

6. Targeting Vulnerable Families: Families in greatest economic and social need and those judged to be most vulnerable to breakdown should have the first priority in government policies and programs.

## Current Implementation Status: Does a Family-Centered Early Intervention System Exist?

There is no systematic ongoing research or programmatic monitoring effort that specifically addresses the degree to which early intervention systems of care are family-centered. There have been national surveys and individual studies concerning the development of state policies to empower families from typically underserved populations (Arcia, Serling & Gallagher, 1992), the development of family policies (Place & Gallagher, 1992), the individualized family service plan process and implementation into early intervention programs (Fewell & Neisworth, 1991; Place, Gallagher & Harbin, 1989), the

nature of parent-professional collaboration (Ooms, 1990), the level of parent involvement in the Interagency Coordinating Councils (Gentili, 1990), and the participation of families in special education (Garwood, 1989). The findings of these studies indicate that parents are involved in the advisory functions as required by law and are involved in the development of their children's service plans. The degree to which parents are truly partners in the care of their child's care or involved in all decision-making functions at the local, state and federal level has not been studied.

Although there have been pilot initiatives in some programs and states using Enhancing Quality to assess clinical programs for children with special needs, care coordination programs, and states' system readiness, there have been no formal studies using the criteria in early intervention programs or systems. Since it is possible for one part of the service system (e.g., the Individualized Family Service Plan) to be family-centered while other programmatic or systemic components are not, research and policy must be encouraged to study and monitor how well the entire system is doing as well as the individual components.

**Recommendations for Assuring a Family-Centered Early Intervention System**

In order for a family-centered early intervention system to become a reality in America, the following actions are recommended as future steps. The following steps represent a beginning point for discussion and action–not an exhaustive prescription for next steps.

1. Encourage agreement on the definition and vision of family-centered care as a goal. It would be helpful to create a consensus among government (all levels), providers, parents, and policy-makers that a family-centered philosophy of care is a goal that should be nurtured. Including "family-centered" language in statutes, regulations, and guidance would further define the importance of having truly family-centered policies and would encourage discussion of how such policies look in practice.

2. Develop "family-centered" standards of care for the early intervention system. Standards and guidelines of care should be reviewed and developed to incorporate family-centered indicators. Special attention needs to be placed on the measurable indicators of a family-centered system rather than on general statements of purpose or intent. These standards should be used for a variety of purposes: education and training, licensing and accreditation, program evaluations, self-criticism and evaluation, policy development and needs assessment.

3. Develop and implement, at all levels of government, monitoring structures that evaluate and encourage "family-centered" systems. An infrastructure within government in partnership with consumers and other sectors needs to be in place to assure that a family-centered system will be developed and maintained. These monitoring structures should include parents. Rather than offering criticism, they should provide technical assistance and education to improve systems. Although difficult to achieve in monitoring

systems, a balance between compliance with regulations and technical assistance to improve services is the goal for an effective monitoring function. A combined federal monitoring effort, shared by the Department of Education (Office of Special Education Research Services) and the Department of Health and Human Services (Maternal and Child Health Bureau), could enhance the development of family-centered systems at the state and local level.

Adequate staffing and funding of this government infrastructure will be necessary to accomplish this goal; this clearly will be difficult in an era when the general public is critical of government bureaucracy and does not understand the "infrastructure" or systems-development roles of government.

4. Develop a research and policy agenda to study the implementation of family-centered early intervention systems. More documentation and study is needed to describe best practices where family-centered early intervention care is occurring, to give overviews of broad national policy and practice, and to understand the dynamics of implementation at all levels of the system. A desirable outcome of this policy research is the direct link of findings with ongoing practice and technical assistance. Early intervention providers, parents and policy-makers should be much more involved in the design and conduct of these studies in the future rather than be the subjects of the studies. Much more collaboration with state early intervention systems and the research community should be pursued. The model of technical assistance and demonstration funding used by the MCH Bureau would be useful in the early intervention system; for example, grants to states to do linkage studies, evaluations of best practice, analysis of state and program data, and community-based research would facilitate a much richer data-base for practice and policy.

5. Integrate family-centered care into all professional training programs. A major barrier to the implementation of family-centered systems of care is the lack of training and experience of the professionals involved in delivering the care and in designing and implementing the systems of care. Much more attention needs to be placed on the incorporation of the family-centered philosophy of care in medical, educational, allied health and social service training programs.

Anecdotal evidence and policy discussions indicate that there is a large gap between the goals and vision of a family-centered system and the actual practice in local programs, communities, and states. This gap is found between the vision and the practice not only in places that have adopted the vision; there is no consensus in the health, education, and social service communities that the early intervention system of care should be family-centered, as defined above. Part H of IDEA and the Title V OBRA '89 amendments have clearly sparked activity in all 50 states related to the creation of family-centered systems of care for all children with special needs. How effectively these systemic mandates will ultimately work to create insitutionalized, family-centered early intervention systems remains to be determined in the coming decade.

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